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Cox, Nigel and Haigh, Carol (2018) Ethical and epistemological challenges of using published evidence derived from social media: Six questions to ask your undergraduate students. *Nurse Education Today*, 71. pp. 264-265. ISSN 0260-6917

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**Publisher:** Elsevier

**DOI:** <https://doi.org/10.1016/j.nedt.2018.10.010>

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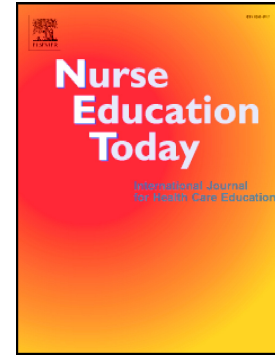
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## Accepted Manuscript

Ethical and epistemological challenges of using published evidence derived from social media: Six questions to ask your undergraduate students

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PII: S0260-6917(18)30876-1  
DOI: <https://doi.org/10.1016/j.nedt.2018.10.010>  
Reference: YNEDT 4000  
To appear in: *Nurse Education Today*  
Received date: 12 January 2018  
Revised date: 2 October 2018  
Accepted date: 24 October 2018

Please cite this article as: Nigel Cox, Carol Haigh , Ethical and epistemological challenges of using published evidence derived from social media: Six questions to ask your undergraduate students. Ynedt (2018), <https://doi.org/10.1016/j.nedt.2018.10.010>

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**Title**

Ethical and epistemological challenges of using published evidence derived from social media: six questions to ask your undergraduate students

**Word count**

1810

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This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

## Keywords

Nurse education; Social media; Ethics; Evidence-based practice; Research critique.

## Introduction

Arguably, the most significant evolution in healthcare research recent years has been the evolution and growth of social media, firstly as a social phenomenon and latterly as a research tool for the generation of evidence. It is difficult to imagine any other social singularity that has shown the longevity and fecundity of Facebook, launched in February 2004, which now boasts on average 1.37 billion daily users (September 2017), or Twitter which has accrued 328 million active users since its inception in July 2006. For many nursing students these platforms, and others like them, have become established social spaces in which to communicate with a range of people, organisations and communities, and hence legitimate places for learning, and knowledge creation or exchange.

Whilst the use of 'big data' (large, digitally mediated datasets) (Brennan and Bakken, 2015) is becoming orthodox and, in the European Union at least, subject to ethical governance and strict legal controls, the use of social media as a source of data remains contested. A number of sources (for instance, Haigh and Costa, 2012; Sinnenberg et al, 2016) have suggested that social media might be used by researchers to illuminate contemporary health issues and, indeed, novice users of research may perceive the extraction of data from social media as unproblematic. However, although orthodox ethical precautions such as the overriding obligation to protect participants and researchers remain prime, a constellation of ethical issues is emerging around the use of social media to provide evidence for practice.

Undergraduate nursing students are usually expected to become skilled consumers of research in order that they may develop proficiency in the delivery of care that is evidence based. This requires of students a critical appreciation of the value and fidelity of research and evidence, and the corresponding digital and technological skills required for their interpretation and safe application to practice (Nursing and Midwifery Council, 2018). In this paper, we explore some of the emergent issues for evidence use via a number of questions that students (and their tutors) should ask of the evidence and strive to answer before choosing to use research findings derived from social media.

### **1. Has the researcher shown safe engagement and disengagement with the online community?**

Many social media websites require users (and hence researchers) to enrol using their offline identities in order to gain access to social media content. Websites may require enrolments to be approved by existing members who act as gatekeepers to participation in the site and (sometimes) as moderators of content. Whereas in the offline research environment gatekeepers are typically better placed to understand the needs of the community and the impact the proposed research may have, the identity and veracity of the gatekeeper in the online environment can be much less transparent. Therefore, students wishing to use research findings derived from social media will need to ensure that they have also critically consider the identity and legitimacy of gatekeeper(s).

Moreover, just as with offline research, ethical consideration underpins the entire research process, meaning that the closing stages of research also require critical consideration. Just as the astute and knowledgeable nursing student will be alert to the researcher's enactment of ethical rituals such as the seeking of consent, they should also be attentive to the ways in which the researcher disengaged from the research environment or community. Sudden or discourteous disengagement from an online community may not only damage ongoing relationships between those who remain within

the community, but unplanned disengagement may also damage the prospect of future involvement by other researchers, and hence the gathering of future evidence.

## **2. Has the researcher demonstrated a critical and ethical appreciation of online identities?**

People who use social media make choices about their identity, and it is not uncommon for people to sustain numerous online identities. Presenting oneself in an online community provides an opportunity for users of social media to create or reinvent a new, temporary or fictional identity that is only used by them when communicating in the online environment. For instance, gender switching is common in cyberspace (Haigh and Jones, 2007) but this may increase the interpretative demands placed on readers and users of evidence that has been derived from social media data.

As such, nursing students should remain mindful that a social media user's stated online identity (e.g. their gender, nationality, or even their medical status) might not always resemble their offline identity. Students wishing to use research that has been gathered via social media therefore need to be mindful of the need for a twofold interpretation: the critical appreciation of published data and evidence, just as would be required when reading an orthodox primary research study, and an additional interpretative step that appreciates research findings through the lens (and lifeworld) of social media.

## **3. Has the researcher explored why people are posting on the social media site?**

Researchers may or may not be closely familiar with the community they are researching. The researcher cannot know the reasons why a contributor to an online social media site has made a particular posting, or chosen to use particular words. For instance, in offline data collection motivation can be explored, clarified and contextualized by non-verbal behaviours but in the online world - particularly when accessing historical, cached or unconsented material - such illumination may not be possible. For the student using such sources of evidence, interpretation can be challenging. For example, text that ostensibly reads as provocative or offensive may, for the poster, represent an expression of 'fact', a cultural belief or political position. Conversely, the post may be designed to amuse or provoke, and not necessarily reflect the individual's 'authentic' position. The student cannot presume that engagement is neutral, altruistic or wholly social: for instance, Ross et al (2009) suggest that some individuals participate with social media principally for the gratification that the number of 'likes' their posts attract and the numerous 'friends' they might accrue.

## **4. Do you have confidence in the fidelity of the reported data?**

Social media communication has been described as producing an 'echo chamber' effect (Goldie et al, 2014) wherein similar views are circulated, amplified (through reiteration or 'likes') and recirculated by the same community of people, with little opportunity for contrary views to be proposed. Unless the original goal of the research was to describe agitated or polarized discussion, findings may only be an artefact of the environment of data collection itself (the echo chamber effect) and hence lack context, complexity and fidelity. Students attempting to use and apply such findings to practice need to remain alert to this circularity: instead of presenting a dependable and fair representation of the wider topic under examination, the findings may simply reflect an unbalanced set of opinions which further impedes the relevance of findings and their transferability to practice.

## **5. Does the brevity of the data create a problem?**

Research findings that are derived from social media may present interpretative challenges due to the counterpoint of data brevity, the rapidly changing or undefined context in which the data were originally collected (for instance, an ongoing event or news story) and the heterogeneity of the

reported data. Microblogging sites such as Twitter may provide data on opinions, preferences or describable experiences, although detecting and understanding sentiment or emotional impact in very short messages is somewhat more challenging. Students need to remain be mindful that, unless the research question is carefully crafted, sufficiently focused, and has standardised processes of data collection, the findings may be of little analytical or practical value.

#### **6. Have the researchers shown understanding of sharing and intimacy within online communities?**

What constitutes 'public' or 'private' in the online environment can be problematic because both of these concepts are metaphors not easily transferable into the online context. From the participant's perspective, Elm (2009) suggests that researcher who use data derived from social media ought to have considered how public or private the original contributors to the social media website believed their words or conversation to be. For instance, an online blog post which, from the blogger's perspective, is a 'conversation' with a discrete number of followers cannot always be seen to be analogous to online content from media organizations whose very purpose is to provide content for wider public consumption. In line with their professional duty to be safe and ethical consumers of evidence, nursing students need to remain cautious about using research that has been gathered from situations where consent has not been fully and transparently secured.

#### **Concluding remarks**

The use of research findings derived from social media or blended online/offline digital communities is an emergent and contested area of evidence based practice. Arguably, data that are extracted from technologically enabled communities may create opportunities for development of evidence that is more responsive to social change and the voices of people within seldom-heard communities (e.g., Cox et al., 2016). This said, for consumers of such evidence, and in particular, novice professionals who are making their first forays into the use of evidence for practice, caution is still required. Whilst many of the principles and practices of research appreciation that apply to orthodox research are transferable to the realms of online research, this new research environment also raises novel ethical challenges for professional and student users of evidence and those who support and guide them to develop their proficiency as evidence based practitioners.

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